



Family News

News and Information for Families of individuals served at Muscatatuck SDC and Madison State Hospital during the transition to community-based services.

MEETING ANNOUNCEMENT

The next meeting of the
**Southeast Regional Project
Team** will be:

March 27, 2002

10 a.m. - Noon

ISTA Building

Second Floor Conference Center
150 W. Market St., Indianapolis, IN
(across from the State House)

HANDY NUMBERS AND WEB SITES:

MSDC/MSH Info Hotline:

1-800-903-9822

www.IN.gov/fssa/transition

Maintained by FSSA to answer
your questions.

DD Waiver Ombudsman:

1-800-622-4484

Available to respond to your
comments and questions.

The Arc of Indiana:

1-800-382-9100

www.arcind.org

www.thearclink.org

A statewide group that advocates
on behalf of people with mental
retardation and related
disabilities and their families.

Area Agency on Aging:

1-800-986-3505

www.iaaa.org

AAAs provide case
management, transportation,
and other services to older adults
and people with disabilities. Call
to find the agency closest to you.

Southern Indiana Center for Independent Living (SICIL):

1-800-845-6914

Part of Indiana's Independent
Living Service system, SICIL
provides people with disabilities
with information and referral,
advocacy and other services.

Deinstitutionalization in Tulsa, Oklahoma

With the support of a grant from the Indiana Governor's Planning Council for People with Disabilities, The Arc of Indiana facilitated a trip to Tulsa in early February. The trip was designed to learn how people with severe disabilities - who once lived at Hissom Memorial Center, a state institution - made the transition from living in an institution to living in neighborhoods. The Indiana group consisted of family members of MSDC residents, FSSA staff, and staff from the Arc of Indiana. This article was prepared by Sally Morris, of the Arc.

Developed as the result of a court order to close Hissom Memorial Center and move all residents into community programs, the system of community programs for people with severe disabilities in Oklahoma is looked on as a national model. While Indiana has a long history of serving people with developmental disabilities in group homes and in small, residential programs funded by the Medicaid Waiver, people who are considered "medically fragile" have typically not been served in small, community based programs. The trip to Tulsa was organized to gain first hand knowledge about their programs, and to meet with state officials, direct care staff, and case managers.

On the first full day of the trip, the group from Indiana split up in two teams, each touring six residential programs. During the visits, there was an opportunity to

talk with direct care staff and case managers; and to see how medical equipment and assistive technology was integrated into typical homes.

The second day of the trip was spent meeting with key staff, including the state nursing director; the training director of Oklahoma State University - which carries out much of the training required for the community programs; the director of the quality assurance program; and the director of ETL (Effective Teaching/Learning), an organization providing direct services and intensive training in working with people with severe behaviors and those who are mentally ill and developmentally disabled.

It was clear from the home visits and meetings that successful transitions were made by careful and detailed planning before people moved into the homes; direct care staff and case managers received intensive, high quality training; a strong system of checks and balances help to provide quality assurance; and that people who had lived in an institution for many years were thriving in their home due to this strong system of supports.

Those who participated in the trip plan to present the information to families and guardians at MSDC. A meeting date for this presentation will be announced.

Family Resource Center

Each month this space will highlight different disability and transition specific print and video resources available to borrow free-of-charge from the Center for Disability Information and Referral (CeDIR), part of Indiana University's Indiana Institute on Disability and Community.

The resources listed here can be obtained by calling CeDIR toll-free at 1-800-437-7924. Borrowers can keep the materials up to four weeks and the material will be mailed directly to your home. The only expense to the borrower is the cost of returning the material via US mail.

This month's featured selections:

- *My choice, your decision* by Advocating Change Together (Video - 1999)
- *Closing the gap: Addressing the needs of people with developmental disabilities waiting for supports* by G. A. Smith (Book - 1999)
- *What's really worth doing and how to do it* by J. A. Snow (Book - 1994)

For more information in CeDir, visit their web site at: www.iidc.indiana.edu/~cedir

An Employee's Thoughts on Tulsa Visit

Becky Smitha, an Occupational Therapist at MSDC who went on the Tulsa trip, reviews her thoughts on the visit.

I liked finding out, seeing for myself, that deinstitutionalization can and does work. If we have the time, resources and supports to design and implement a service system that is responsive 24/7 to residents' needs.

I liked that the homes we visited were the homes of the residents and that the staff and guests were invited in by the residents and their guardians.

I liked that the homes we visited were the homes of the residents and that the staff and guests were invited in by the residents and their guardians. I liked it when the phone rang in Carolyn's house and her companion staff answered the phone "Hello, this is Carolyn's house, Angela speaking".

I liked that parents took the time to come meet us and tell us about how scared they were about their son or daughter leaving the institution several years ago; but that now, after a lot of hard work and some rough times, things are good and that

they are happy about the move into the community.

I liked how the Administrative staff say that their system is NOT perfect, that they are still learning things and changing things and that they don't ever think it will be perfect - because if things are perfect, where is the motivation for change and improvement?

I liked it that there was a clear and reasonable answer for every single question I asked the staff about a resident.

What impact does the visit have on me and how I view the transition process? We have a way to go before we can say those same things that I wrote above about the Southeastern Region here in Indiana. There are a lot of good people working on the planning now. I want us to take the time to do this thing right. The residents and guardians are counting on us to make it work, to make it come true in Indiana just like it is coming true in Oklahoma.

INTERNET ACCESS RESOURCE CENTER

Many articles in this newsletter direct readers to the Internet sites of various organizations. We hope the sites listed will be helpful to readers as they gather information about the transition and the resources available in the community. Continuing this month and in future editions, we will list locations in southeastern Indiana where the Internet can be accessed for free.

CLARK COUNTY

Jeffersonville Township Public Libraries

Downtown Jeffersonville branch

211 East Court Avenue

Jeffersonville, Indiana 812-285-5630

8 computers in adult services (1 hour limit per day), 2 more for 15-minute e-mail access.

Users must present library card or photo ID.

Clarksville branch

1312 Eastern Boulevard

Clarksville, Indiana 812-285-5640

3 computers for adult use (1 hour limit per day) 1 more for 15-minute e-mail access.

Users must present library card or photo ID.

DEARBORN COUNTY

Aurora Public Library District

Aurora Public Library branch

414 Second St.

Aurora, Indiana

(812) 926-0646

5 workstations, 1 for Spanish language, 30 minute limit if others are waiting, must sign policy statement.

Dillsboro Public Library branch

10151 Library Lane

Dillsboro, Indiana (812) 432-5200

5 fworkstations, 30 minute limit if others are waiting, must sign policy statement.

FLOYD COUNTY

New Albany-Floyd County Public Library

180 West Spring Street

New Albany, IN 47150

812-944-8464

18 computers, 1 ADA compliant

1-hour limit if others are waiting.

OHIO COUNTY

Ohio County Public Library

100 North High Street

Rising Sun, Indiana 47040-1022

(812) 438-2257

5 public terminals.

30 minute limit if others are waiting.

SCOTT COUNTY

Scott County Public Library

108 South Main Street

Scottsburg, IN 47170

(812) 752-3425

5 terminals, must sign policy statement.



Other Views

Below is the second in an occasional series of guest columns by leaders in Indiana's disability advocacy community.



by Costa Miller
Executive
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Indiana
Association of
Rehabilitation
Facilities, Inc.

Change Is Inevitable

Change is inevitable. No matter how hard we try or how deeply we hope that "things stay the same," change happens. Change is not necessarily bad, not necessarily good. Change is life.

The key to change, the key to unlocking the joy of change, is how each of us deals with the unavoidable circumstance that is change.

Change can be dealt with in many ways, including:

- Resistance.
- Transition.
- Support.

Currently, Indiana's total system of services to people with developmental disabilities is undergoing change. The most dramatic aspect of the change focuses upon where a person will reside. There are many reasons driving this change: Federal policy, federal court rulings, state policy, economics, quality of life, improvements, parents, guardians, and - most importantly - the choice of the consumer.

Indiana's residential system for people with developmental disabilities has been in gridlock for many years, primarily because of benign neglect. But the tide began to turn with the state's initiative known as "the 317 Plan." While we are not

where we need to be - because barriers to the fullest possible quality of life still exist - we are making steady progress in eliminating those barriers.

But there's that word again, change. For many of us, it was easy to confront change with Option 1 - resistance. Who wants to change under less than reasonable circumstances? So, amid uncertainty, we resist change, even though change will inevitably continue to occur in some form or another.

The consequence of resistance, however, is that change may take a direction contrary to its intended purpose.

Option 2 is Transition. What is the change at hand, and what consequences will it have on us? On me? We can adopt a "go with the flow" approach, or we can take a "hands-off" approach. The problem is that neither approach will affect change. Just as with Option 1, we will be left standing on the sidelines.

Which brings us to Option 3 and the gist of the issue. Change is coming to Indiana, and under the right direction it is change that will benefit all Hoosiers, not just people with developmental disabilities.

Change can be positive - and there is rock-solid evidence that such is the case here. You have endured the uncertainty, you have shed the tears of fear - but now that resistance and transition have passed, you can move on to support. You can enjoy change, which is the way of life itself.

Change is coming. Change is here, caused by external forces that we may or may not be able to see.

The answer to success - and to the sense of security we yearn for so much - is to focus on supporting the person who is making the choice. If we do that, we can all move in the right direction.

Family and Employee News Now Available On-Line

Both the *Family News* and *Employee News* newsletters will now be posted on-line each month. FSSA's Muscatatuck/Madison Transition Process web site has added the newsletters as a feature.

The web page can be viewed at:

www.IN.gov/fssa/transition

Contact Us!

FSSA maintains a web site, a toll-free phone number, and this newsletter to keep MSDC and MSH families fully informed.

Anyone who would like to receive this newsletter can call the number listed, leave their address, and be added to our mailing list.

The web site features questions discussed at family and employee meetings, the final report from the Governor's Council on State Operated Care Facilities, updates on the *Olmstead* process, articles, and more.

You can visit the web site at:

www.IN.gov/fssa/transition

If you have questions, comments or concerns, or want to request copies of items on the web site, write to:

Secretary, FSSA
402 W. Washington St.,
Room W461
Indianapolis, IN 46207-7088
Attn: MSDC/MSH

or email:

OfficeOfTheSecretary@fssa.state.in.us

or call toll-free, 24 hours a day:

1-800-903-9822

You can also call this number if you have concerns about the services that your loved one receives after leaving MSDC or MSH.